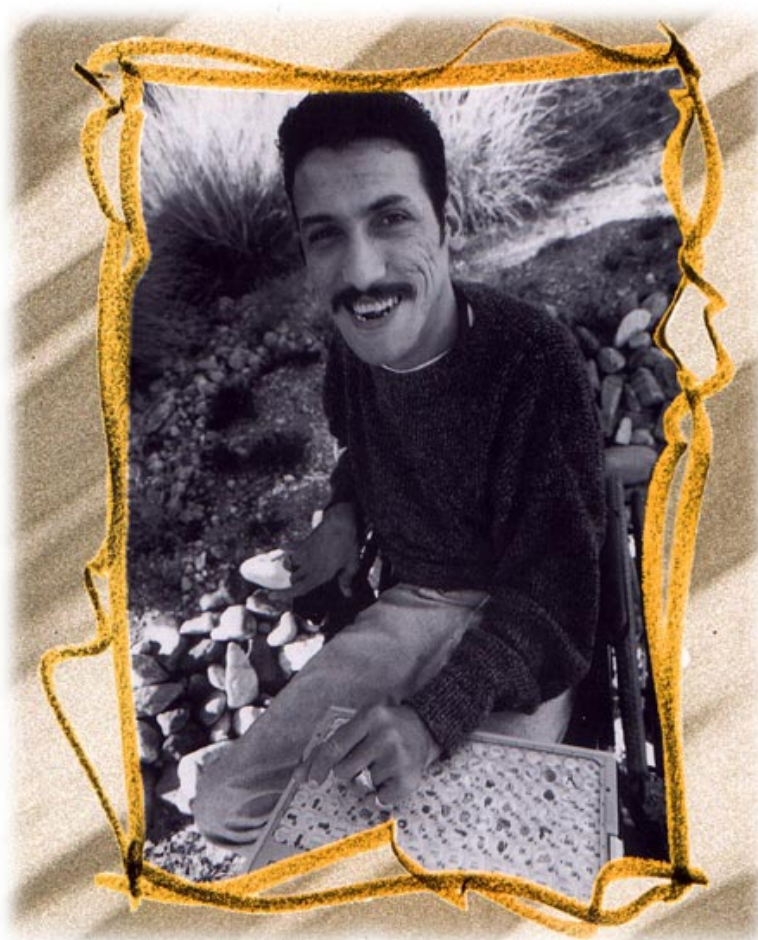


Desert Stars

Arizona Stories of Transition to Adulthood



Jenny Mish & Rena Bonesio, MSW

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Dear Reader,

Welcome to Desert Stars: Arizona Stories of Transition to Adulthood! The stories in this book are based primarily on interviews with Arizonans who have developmental disabilities and their parents or close supporters. They represent an array of cultures, communities, types of disability, lifestyles, and interests. They offer peer role models who may actually be a lot like you, or like someone you know.

As you read this volume, you may not think that these young adults have severe disabilities because of what they have accomplished. Each person in this book has been assessed and diagnosed, with labels ranging from moderately mentally retarded to severe multiple disabilities, from fetal alcohol syndrome to learning disabled.

In our interview, we asked people to tell us about their lives, what they have figured out, and what advice they have for others. We didn't ask about limitations, social weaknesses, and unsolved problems. We didn't ignore the challenges, but we learned about them in a positive light, which is how we want to pass them on to you. We think this difference is at the core of transition to adulthood: people with disabilities are people first, people with gifts and contributions to offer. Our hope is that this beginning collection will inspire many more success stories. Whether you have a disability or not, whether you are a parent or other family member, a professional or other supporter, we hope that this collection of vignettes will leave you with new ideas and enthusiasm.



A Note About Personal Futures Planning

A number of the stories in this handbook refer to circles of support, personal teams, or Personal Futures Planning. These are ways of gathering (or finding) close friends and supporters to help with planning and creative problem-solving so that a person can get the support they need to live the life they want. If you want more information about these tools, or want to use them in your family, you can ask that this style of planning, person-centered planning, be used to develop your IEP, ISPP, IWRP, etc. You can also contact us at Pilot Parent Partnerships for more information.

**Mark Mendibles:
Never Give Up**

Mark is 19 years old. He graduated from high school with a GPA of 3.47. He is very proud because it took a lot of work. He even won an achievement award from his school district called the "I Can Do It" Award. Mark says that he gets a lot of support from his family and friends. In describing what kind of support they give, he says, "They make me laugh." He explains that humor and communication are the things which best help him to get along in life.



Mark is now enrolled in classes at a community college. He is very people-oriented, and he loves spending time talking to people. In fact, he had been working towards becoming a drug and alcohol rehabilitation counselor, but then he switched to computer programming so that he would be able to create programs for people with disabilities. Mark receives support from Vocational Rehabilitation for college and he says, "They've been really great." VR pays for his classes and books. Mark's parents are also very supportive of him in his schooling. When Mark went to buy his books and familiarize himself with the campus, his parents went with him. They followed him and allowed him to find his own way around, which is challenging because it is a big campus. It is also challenging because Mark has to find ramps and elevators. They went with him to support him, yet they let him fend for himself.

Mark's mother explains that watching Mark grow up has not been easy. She has been learning to let go. She says that Mark is always reminding her, "Mom, I'm not a baby." She said letting him grow up was



Sometimes he acts, other times he dances with his wheelchair. Mark has especially enjoyed giving talks at workshops to teach people about the strengths and abilities of people who have disabilities.

a little easier for her because she worked as a teacher's aide at his high school, and was able to see him mature in his dealings with other people. However, she still struggles and worries for Mark and his safety. For example, since he does not see well, she is afraid he might accidentally go down some stairs instead of a ramp. Her husband has been very helpful, though, in encouraging her to let go and let Mark have his independence. His parents are very proud of him and how well he is doing.

Mark has found that one of the new responsibilities of adulthood is arranging for his own transportation. Mark is living with his parents, but they made sure he has his own phone line and answering machine so that he can have the freedom to make arrangements for transportation and other things in his life. Since Mark uses a wheelchair because he has cerebral palsy, his transportation options are somewhat limited. He uses a local van ride system



to get around. He finds that the system is not always adequate for his needs, though, because reservations must be made a week in advance, which does not allow for a lot of flexibility or spontaneity. Otherwise, he has to get a ride from his family or friends.

Mark has been very actively involved in a local theater company called Third Street Kids. It is an internationally recognized performance company which consists of young people who have disabilities who educate their audiences on disability awareness. Mark has been a part of the group since it first began about twelve years ago. He has done a lot of traveling with Third Street Kids, including performances in Seattle, Boston, Washington D.C., Hong Kong, and Mexico. Sometimes he acts, other times he dances with his wheelchair. Mark has especially enjoyed giving talks at workshops to teach people about the strengths and abilities of people who have disabilities. According to Mark, Third Street Kids has been “very gratifying,” not only because of his personal satisfaction in helping to educate people, but also because he has made many friends there. It’s kind of sad, but Mark is having to wind down his commitment to Third Street Kids so he can pursue his college career.

Mark says that becoming an adult has been a struggle, but he’s making it. He has this advice for young people: “If you don’t try for yourself, you’re not going to get anything accomplished. You’ve got to keep motivated. If you’ve got the right motivation, you can accomplish anything. If you ever get down on yourself, just realize there’s always a light at the end of the tunnel. Never give up. If you fall off the horse, get right back on. That’s how I look at life.

-Tucson, AZ

Key to Success

Key to Success

Although Mark’s parents have provided the supports he has needed, they have allowed him to fend for himself, finding his own way, and developing his own solutions.



Glen Yazzie:
It's the Adult Thing to Do



Glen is 23 years old. He is Navajo and comes from a family which remains strong in Navajo traditions. Glen's family is very talented: his mother makes jewelry and rugs and his father paints. Since his dad paints, Glen tried his hand at painting and found that he does fairly well at it. But Glen's family kept trying new things to discover areas where Glen excels. Now Glen is very skilled at making dream catchers, and he has been very successful at selling them on the reservation. Glen's family, which includes not only his parents but also quite a few siblings and extended family members, seeks what works best for him rather than trying to fit him into some preconceived mold because he has Down Syndrome. They are very supportive, but they have not limited him in what he can do. In fact, they have really let him spread his wings and fly.

Glen's parents are very proud of him because of the maturity he has shown in his current job and in the crafts he makes. These are responsible things which adults do. Glen has been working at Burger King for about two and a half years, since before he got out of high school. He takes care of the dining room and he enjoys interacting with the customers. He knows when he needs to be at work, how long it takes to get there and when he needs to arrange for his own transportation. He makes sure he gets there, even though he lives a 45 minute drive from Page, where he works. Glen is fortunate that he has a large extended family which often helps him with getting to work.

Glen's life is the same as would be anyone's who is deeply connected with the Navajo culture. He herds sheep, he makes crafts which he sells, he is regularly involved in his community and he participates in his

community's religious ceremonies. Glen benefits from participating both in his Navajo community and in the community of Page. People who live on the reservation and people who live in Page enjoy visiting with Glen at his work and they ask about him when they haven't seen him for a while. Since the schools in Page regularly include the students naturally get to develop relationships with other people in town. It is nice to live in a small community whose population cares for each other enough to ask, "How are you doing?"

Glen has grown a lot over the years. He is very perceptive and he knows when it is appropriate to be silly and when it is appropriate to be serious. When he was in high school, he acted like a high schooler. But now that he is an adult, he acts like an adult. Shortly after graduating from high school, Glen began drinking coffee. Suddenly, whenever he would arrive at the home of his service provider, he always had a cup of coffee from Circle K. When his provider asked him why he started drinking coffee, Glen simply replied, "It's the adult thing to do."

Glen lived independently in his own apartment in Page for a year. He moved back to the reservation to live with his family because there were just not enough services available in the small town. Now, Glen is able to get the support he needs from his family and the other people in his community. Glen likes living with his family, but he really liked living on his own and he would like to have a home of his own again. In fact, he and his family are working with his tribal government and local community to arrange for Glen to get his own home. He just needs some support as he works to



Glen's life is the same as would be anyone's who is deeply connected with the Navajo culture. He herds sheep, he makes crafts which he sells, he is regularly involved in his community and he participates in his community's religious ceremonies.



Key to Success

1. Glen is responsible for arranging his own transportation from one small town to another for work. He is able to do this because he can rely on a large extended family and community support circle who care about him.

2. Glen and his supporters learned a lot from his year in his own apartment, and he is not giving up on his dream. Even in a small town, living independently is a realistic goal.

to improve his skills in cooking, finances and other typical “bachelor” things. It is also important to Glen to have plenty of people to socialize with when he is living on his own. Therefore, having opportunities to make friends and enjoy other meaningful relationships is one of the issues Glen, his family, community and service providers know must be addressed in order to meet Glen’s needs and to help ease the transition to his own home.

Glen really loves learning and applying new knowledge in his life, whether it’s academic skills, work skills or personal skills. He also likes to have fun. He is a good looking young man with dreams for his life. He is looking forward to moving out of fast food and pursuing his interest in carpentry. With his maturity and determination and his family and community support, Glen is more than likely to success. He already is a success.

-Marble Canyon, Navajo Nation



**Erika Jahneke:
Holding Her Ground**

Erika is 23 years old. She is a student at Arizona State University where she is majoring in journalism with a minor in English. Erika is planning on completing her Bachelor of Arts degree in 1998. She really enjoys writing and she hopes that one day she might be able to write fiction as a career.



Erika arranged for some accommodations at school, including a note-taker for her classes, extended time for tests, and someone to write her test answers for her. The school also provides a place to recharge her wheelchair battery, and a loaner chair when hers breaks down. Even though they have an office to provide these services, Erika finds it hard to ask for things at times. Fortunately, she has had some practice.

When she first moved away from her parents, Erika lived in a supported living apartment, but the staff turnover was so high that it was difficult to build trusting relationships with personal attendants. After that, she tried a group home for about nine months, but she says, "I was pretty bored and depressed there because it just wasn't where I wanted to be—it's kind of what I was left with."

Finally, Erika signed up with an agency that matches personal care attendants with people who need them. Now she has her own apartment, and her personal attendant is her roommate. She learned by trial and error how to find someone she is happy with. Erika explains that finding a personal care attendant is hard because there are a lot of preferences and details that need to be worked out before a person can rely on someone else to do things which are personal.



In order to get into his office, a big man actually stepped over her and her wheelchair. She was pretty shocked that someone would be so bold. She didn't move, though, and she held her ground. She was quite glad that big man did not fall on her!

At the time of the interview, Erika had just returned from a successful trip to Washington, DC with the activist organization ADAPT. She spent six days there doing activist work. For example, a few hundred protesters, most of who use wheelchairs, stayed in the rotunda of the Capitol Building until midnight one night to support a law to expand in-home services rather than forcing people into nursing homes in order to get simple attendant care. They also spent time around the representative's offices, handing out copies of the bill to increase awareness of the importance of the issue.

One day while she was in Washington, DC, Erika participated in a protest to get Greyhound busses equipped with lifts. Erika had run into accessibility barriers on Greyhound when she and some friends planned a trip to Tucson. Erika related an incident at the protest in which she was helping to block an entrance to the Greyhound building. In order to get into his office, a big man actually stepped over her and her wheelchair. She was pretty shocked that someone would be so bold. She didn't move, though, and she held her ground. She was quite glad that big man did not fall on her!



Erika admits that going on the ADAPT trip was a big step for her. She took physical risks because the hotel shower was not very accessible, food was not always available, and she had to stay up late at night for the protests. In some ways it was pretty scar for her. From this experience, however, Erika learned that she can "deal with rough situations and not fall

fall apart.” She had doubted for a long time if she would be able to do it all, raising the money, and finding and training a personal assistant who could go with her. But she found that going through with the experience has increased her confidence in herself and the larger community of people with disabilities. She says, “It was pretty amazing for me to be in contact with so many other people with so many other disabilities.”

Erika has recently started a Personal Futures Planning circle. So far, her team has supported her in writing a resume so she can find a journalism internship before she completes her degree. She explains that one of the best things about her circle is that it provides some accountability. She knows from experience that she is more likely to take care of important tasks when she knows someone will ask her if she has done it.

Erika does not boast about her life’s successes. In fact, she tends to point out negative things about herself. But she has many good things to be proud of. She has her own apartment and a good relationship with her attendant. She raised the money and went to Washington to stand up for something she really believes in. And she is getting a Bachelor’s degree despite various difficulties. For Erika, being successful means maintaining high expectations of herself, even through life’s disappointments and challenges.

—Tempe, AZ

Key to Success

1. By joining with other people with disabilities to stand up for civil rights, Erika made an important contribution and discovered much more about her own abilities.
2. Erika learned a lot from trying different living situations and personal attendants; now she has her own apartment which she shares with her roommate/attendant.



**Kevin Carpenter:
Doors of Hope**

Kevin is 23 years old and he has an apartment of his own. Getting to this level of independence has taken some dedicated work from Kevin and from his transition team, including his mother. Kevin has autism, is deaf, and has a little bit of a vision impairment, too.

Working at the food stamp office counting coupons and receipts, Kevin is a self-supporting young adult. He makes enough money to pay his own bills. He leads a simple life and he's happy with what he has. Admittedly, Kevin is not very good at managing his own money (his family helps him out), but he really understands the value of earning money and the need to work so he can enjoy his own apartment. According to Kevin, being successful means having the "good things" in life, like enjoying family, having a job and his own apartment.

Kevin's mom remembers the day he got his studio apartment. She has always figured that Kevin would have to live in a group home. But Kevin was adamant that he wanted his own apartment and one day she finally thought, "Why not?" So they went down, applied for the apartment and he got it. "And then," She says, "I went home and I thought, 'What have I done?!'"

After Kevin got his own apartment, his attitude toward doing things for himself really changed. He became interested in doing more things independently. For example, now Kevin wants to know why he can't drive. He keeps coming back to this question. Finally his mother has said, "I don't know. Maybe you can. Maybe you should go and take the vision test." Kevin and his mom aren't sure if his vision and his coordination will be good enough, but Kevin seems determined to try. According to his mother, sometimes you just need to take risks.

Kevin says that for him the major difference between being a teenager and being a young adult is that, "When I was a teenager, I did not understand what a job was and now I have a job." Kevin really likes his job coach who helps make sure Kevin does his job right. The job coach also teaches Kevin new things for his job, which is really great for Kevin, who says, "I love to learn." Kevin enjoys learning so much that he is an avid Sunday school attendee at his church.

Kevin got his first job through his school's vocational program. That work experience was really great because it took him outside the school environment. He was working for an insurance company which eventually folded—everyone at the company lost



Kevin was adamant that he wanted his own apartment and one day she finally thought, "Why not?" So they went down, applied for the apartment and he got it. "And then," She says, "I went home and I thought, 'What have I done?!'"



PHOTO: FRED GRIFFIN

Key to Success

1. Kevin's job success builds on the real-world work experience he received in his high school community-based vocational program.
2. The Personal Futures Planning process was used to organize a team of people with the information and resources needed to make Kevin's dreams into realities.

their job. Kevin's transition team helped him look for a new job and it took about three months for him to get his current job. During that three month period, the pressure was really on because Kevin did not want to lose his apartment for lack of rent money. With the help of his mother, he applied for regular jobs in the community and they took an interpreter with them to the interviews. Did they discuss Kevin's disability at the interviews? His other says, "I didn't point it out and nobody asked."

Kevin's mother feels that transition is very scary and that it's hard. She explains that parents spend a long time with the school system, focusing on all that the schools do for the child. School can provide a lot of structure, but no young person can stay in school forever. In order to help Kevin transition into young adulthood, Kevin and his mother used the Personal Futures Planning model which brought together a team of individuals including teachers, family, and people from Vocational Rehabilitation and the Division of Developmental Disabilities. Kevin's mother explains that this group still works with Kevin to help him identify and implement his dreams.

Kevin's mother believes that the Personal Futures Planning process has really opened doors of hope to things she never thought were possible. It has encouraged her to say, "Why can't Kevin do that?...What's standing in the way?" He has just needed some supports to become as independent as he is today. In reflecting on how far Kevin has come in his life as a young adult, she remembers, "Never in my wildest dreams..." She wants to tell other parents to take risks and to let the young person try new things. It can be really scary, but it pays off in the long run.

—Phoenix, Arizona



**Manual Dominguez:
Dancing to the Rhythm**

Manual, who also goes by “Manny,” is 21 years old. Like most young adults, he loves music. He likes ranchera and country music the most. *Selena* is his favorite artist. According to his mother, when he hears her music, he waves his arms in the air, dancing to the rhythm.



Manny is in the twelfth grade, and is proud to be a Safford Bulldog. He enjoys school very much, and is especially fond of one of his teachers, Mrs. Cunningham. Manuel has a lot of friends in school. His mom chuckles, “He likes to flirt with all the girls.” Manual likes trips to the store and loves to go places with his family. Everywhere he goes, he knows how to turn on the smiles to grab a young lady’s attention. In fact, he is a master of body language, and saying things with his face and eyes. When he looks up, he means yes, and a glance left or right means no. When he wants to add emphasis, he makes sounds, waves his arms, or even dances in his chair.

Manuel saw a video of Bob Williams, US Commissioner of Health and Human Services, who uses a communication device called a “Liberator” to give speeches and do his job. Manny grinned from ear to ear and waved his arms with excitement. If he had such a device, it would make a world of difference in his life.

On a trip to Tucson last year, Manuel met Gus Estrella, who remembers being in Manny’s situation, not knowing if or when he would be able to express his ideas in words. Now Gus uses a Liberator and works in Washington, DC (see Gus’s story). Gus told Manny and his mother not to give up hoping and working for a communication device.



His mom met with his IEP team and exercised her right to transportation for him. Now, if the designated bus breaks down, the school has an alternate van that they send to pick Manuel up for school.

When he was younger, Manuel's school provided a communication board. But it quickly broke down, and for years he had no access to such a device. Recently, his school bought a new one. Unfortunately, Manny can't use the new device without a helper.

His school is working closely with DDD to purchase yet another communication tool which truly matches his needs, one that he can operate on his own, and that he can take with him wherever he goes. Manuel's mom would like him to be able to communicate all the time, to say what he likes and doesn't like. Of course, Manuel wants that, too. He wants to communicate, use a computer, drive a car, and have a job.

These dreams are getting closer now that Manuel's mom has been learning more and taking more initiative to get the things he needs. Since Spanish is the language she uses, it hasn't been easy getting needed information. She has asked many times for the school to provide paperwork in Spanish, and this is finally starting to happen.



Manuel's mom recently asked that a comprehensive evaluation be done in Spanish, using an augmentative communication system, to find out more about Manny's abilities. The evaluation showed that his capabilities are well beyond previous expectations. The only other time he was tested in Spanish, his scores were much higher than on test in English.

Manuel's mom is learning how to make sure that all of her son's abilities are taken into consideration in planning for his future. Unfortunately, she may need to use these new skills again and again. For example, Manuel was recently denied eligibility for Vocational Rehabilitation, because they said he was not employable. But Manny's mom remembers meeting Gus Estrella, and it's not clear to her that her son is unemployable.

Manuel and his mother have faced many obstacles. Even though there have been tensions in their family and with school officials, the communication is improving. The Dominguez's started a Personal Futures Planning team, and began to identify Manuel's needs and find ways to get them met. For example, the team recognized that Manny didn't have full access to the house he lives in. His DDD Support Coordinator put through the paperwork to buy materials, and Manuel's father, brothers, and a close friend widen the bathroom door and installed more useful cabinets. DDD also provided a much-needed wheelchair lift for the family van.

Recently, Manuel and his mom had a breakthrough with the transportation department at school. Before, the bus that came to pick Manuel up for school would break down frequently. Many times, the family van had mechanical problems, so he simply stayed home. His mom met with his IEP team and exercised her right to transportation for him. Now, if the designated bus breaks down, the school has an alternate van that they send to pick Manuel up for school.

Manuel and his family still have many obstacles to overcome before he will have a life of his own, but the successes are adding up. With a few accomplishments behind her, Manuel's mother has gained new confidence, and is starting to share the information she is learning with other Spanish-speaking families. As for Manny, his dreams are eagerly waiting for the day that he can express them in detail.

—Solomon, AZ

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Key to Success

1. In the face of setbacks, Manuel's mother has become more assertive and persistent in order to get needed information in Spanish, appropriate evaluations, home modifications, transportation, and assistive technology for Manuel.
2. Exposure to two successful role models has proven that the resources Manuel needs are possible to attain.



**Tom Brownlie:
Growing Seven Days a Week**

Tom who is 26 years old, describes himself as generous and trusting. He has Down Syndrome. He likes to lift weights, listen to music, watch TV and go bowling. Tom especially likes hanging out with his friends, including having pizza parties and jam sessions on the drums.

Tom's family felt that the transition services at his high school were limited. There were work opportunities available on campus, such as working in the cafeteria and doing custodial work, but the school hadn't developed job placements in the community. Tom's parents insisted that he get some experience working off campus. He worked after school at Peter Piper Pizza for two years toward the end of his schooling, with a job coach provided by DDD, but he got tired of it, gave notice to his boss, and decided to get another job. At that point, Tom's parents felt pressured by the transition services staff to have Tom work in the local sheltered workshop, because there were so few options available in their small community at that time. Bowing to that pressure, Tom ended up working at the sheltered workshop for about a year, but he did not like it at all and he let his parents and supervisors know how he felt.

Tom decided for himself that he did not want to work at the sheltered workshop any more. He went to Wendy's, picked up an application and got a job for himself. The staff from the sheltered workshop did not believe that Tom was capable of working in the community. They wanted to "support" him, so they sent a job coach with him after he got the job. Actually, Tom felt that he did much better after he "got rid of the job coach" because the job coach was insisted that Tom cook French fries when Tom was certain that was

something he did not want to do. Tom has been working at Wendy's for almost two years now. His primary responsibility at work is keeping the dining room clean, but he also tends the condiments stand and occasionally cleans the restrooms (Tom likes having diversity in his work). Tom's boss says he is doing a great job and that he can rely on Tom to get his work done. Tom doesn't want to feel limited in the area of employment though—he has plans to move on to a different job in another year or two, perhaps at a movie theater.

Several years ago Tom's parents and Tom's aunt bought a small home for Tom and his cousin (who also has Down Syndrome) so they, with some support from



Tom decided for himself that he did not want to work at the sheltered workshop any more. He went to Wendy's, picked up an application and got a job for himself.



PHOTO: FRED GRIFFIN

Key to Success

1. Tom's family felt that his school was lacking a program for students to get community work experience in their small town, so they insisted that a real-world job would be part of his high school education.
2. Tom's parents realized that unless he moved out on his own, he wouldn't be able to develop his own independent adult life. It was what he wanted, and even though it was hard, they helped make it happen.

a live-in DDD staff person, could live together. They had some problems getting along with each other, though, and they decided that it would better to be friends rather than housemates. Tom gets along with his current housemate much better, which is very important to him. He also likes being in town rather than living with his parents who live about eight miles out of town—it's a lot more fun being closer to the action and having to rely on family members for transportation.

It was scary for Tom's mom when he moved out, but she and her sister had been planning what they wanted for their sons, since they did not want them to have to stay at home. Also, Tom had made it clear that he wanted to move out of his parents' house. Tom's dad admits that they, as parents, were not always the best trainers for Tom, and that it was often easier to do things for him rather than allowing him to do for himself. For them, it was important to have Tom move out of their home so they could let him do things for himself. According to his father, "It was good for tom and it was good for us."

Tom's current goal is to live on his own without a paid staff person. His residential staff person is providing some great training for him and Tom is very willing and capable of learning. She is helping him learn to be more responsible, such as getting himself up in the morning on his own. Tom has much to learn on his journey toward becoming more independent. As Tom puts it, "I'm growing right now, you know, seven days a week. Its not easy, but it sure is worth it!"

—Prescott, AZ

Marisa Urbina: A Little Spice

Marisa is 15 years old. This is her first year at a big high school, where she is enjoying getting reacquainted with classmates she knew in elementary school. Marisa likes school. She has been included in regular classes since the fourth grade. Marisa's mother used to help out a lot so that people would know how to have conversations with her daughter, but more and more Marisa has taken on that role herself. She interacts with other kids all day at school. And even though Marisa eats separately rather than in the chaotic cafeteria, she always has some of her friends join her and they all "do lunch."



Marisa is like any other 15 year-old in that she spends a lot of time hanging out in her room, her haven. Marisa especially likes early rock 'n' roll like Elvis. One day, she was listening to "YMCA" by the Village People, and she and her mom interrupted their morning routine to do the motions. Her mom held out Marisa's arms for her, spelling out "Y-M-C-A." Marisa had a blast!

Marisa is definitely in tune with what's cool. She wears vanilla cologne and make-up, and she likes earrings, too, which her mom is always trying to borrow. She wears clothes that are in fashion; even though her mom would like her to wear pastels, Marisa chooses darker, more serious colors with simple designs.

The two of them like to go clothes shopping together. Since Marisa has a vision impairment, her mom presents the clothes close to her and asks questions like, "do you like this one or that one?" or, "Do you want to touch this one?" In this way, Marisa gets to choose her new clothes. In the mall, Marisa and her mother travel side by side rather than her mom pushing her wheelchair from behind. That way, they can interact better, and it demonstrates the respect mom has for her daughter. Marisa's mom knows she is a role model, showing others how to interact with



people who have disabilities.

“Once in a while,” she explains, “someone will say to me, ‘We don’t have money for that.’ And I look them in the eye and ask them to put it in writing.”

Although Marisa cannot speak with words, she is skilled at indicating when she wants to be alone. An angry noise or a “sneer” (“she developed that wonderful sneer at age twelve”) clearly says what Marisa does not like or want, and a smile or a laugh indicates something she likes or wants. Marisa’s parents try their best to respect her needs and desires, whether that means spending time alone in her room, wearing make-up to school, or not having mom borrow her earrings. From the time she was very young, her parents have encouraged their daughter to make decisions and express preferences, even though they don’t always agree with or like her choices. They even had a goal of being able to say “no” as part of her IEP. Marisa’s mom explains that she wanted to raise Marisa to be her own person. “I want a child that’s got a little *spice*.”

Last year, Marisa’s IEP focused on transitioning into high school. For years, her IEP team had been meeting every month to work out potential problems. When no one from high school came to any of the first three transition meetings, Marisa’s mom became concerned. Her concern



was written in the minutes, and she sent copies to the administrators at the high school. From then on, high school staff were always at the meetings. As it turned out, they needed those monthly meetings to plan accommodations for health care and personal needs. They even had to tear down a wall to make the high school accessible for Marisa!

Marisa's mom is interested in working cooperatively with school staff, which is what they want, too. She knows her rights as a parent. "Once in a while," she explains, "someone will say to me, 'We don't have money for that.' And I look them in the eye and ask them to put it in writing." It has never happened, but if it did, she would send copies to the appropriate government offices to ensure that Marisa could receive the education she's entitled to.

While school is going very well, Marisa's mom confesses that it is difficult to plan for her daughter's transition to adulthood. She has real concerns about adult systems, about the opportunities that will be available for her daughter, and whether or not Marisa's choices will be respected. Even more, she recognizes that she will no longer have the same level of input into her daughter's care. "Marisa is like a potpourri, a little of everything," she explains. "To professionals in the field, she's multiply disabled, severely so, but to Mom, she's Marisa." Marisa's parents are hoping that perhaps she can have a provider who lives with her in her own home. They know that it will take creativity and dedication, but they sadly realize that they cannot provide for Marisa's needs forever.

In the meantime, Marisa and her family relish her successes. It was a big success when physicians began talking to Marisa directly, after years of watching Marisa's mother ask her daughter the same questions they asked her. And success can mean a great day at school, where Marisa influences the other kids, making them more respectful and appreciative of people who have disabilities.

—Phoenix, Arizona

Key to Success

1. Marisa's parents have been dedicated to making sure that Marisa can make her own decisions and communicate them to others.
2. Knowing her legal rights and what to do if they are not met, Marisa's mom has been able to ensure the best education available for her daughter.



Joe Hill:**If It's Going to Be, It's Up to Me**

Joe is 28 years old. He describes himself as a loving and caring person who tries to lend a hand to people in need. He says he is fortunate to have his family, and he claims that he has “the best parents anyone could ask for.” Joe appreciates his parents greatly, but he is no longer dependent on them. His personal philosophy is reflected in a motto which hangs on his wall: “It its going to be, it’s up to me.”

Joe is not able to use conventional speech. His experience of transition to adulthood included finally being able to speak with other people through the use of an augmentative communication device. When he got his first machine, as his father put it, it was “a miracle” because Joe could finally speak and communicate with his family. Up until that time, Joe’s parents had made most of his decisions for him. When Joe was born, they were told that they had two options: to put him in an institution or to take care of him themselves, which they figured would be for life. They had [Joe’s parents had] no idea that Joe could ever be independent and it simply never occurred to them that he would need decision-making skills in order to function as an adult.

It was difficult for Joe’s parents to get used to allowing him to decide things for himself. Even Joe has had a hard time learning not to go to his parents whenever he has a problem. When asked if there was anything he did or that he wished he had done to make the transition easier, Joe replied, “I wish my parents had taught me more how to take care of myself at a younger age.”

Joe began participating in Personal Futures Planning when he was a junior in high school. It really helped him to begin to thing about new possibilities in life. Now he lives in an apartment of his own and he is working two

jobs. Joe enjoys answering phones and greeting people at Sage, where he is a receptionist. His other job is a part time position at the police station where he does data entry using his head stick. He says it can be kind of boring, but he likes it because, as he says, "It keeps me busy and out of trouble." He is currently getting some help to search for another job which he would like better. Joe describes himself as "a people person" and so he is particularly interested in getting a job working with people.

Joe candidly explains that he has experienced many successes as well as some failures. For Joe, being successful means getting along with people, looking toward the future, and focusing on goals. He says that while he has some really good people in his life, he still needs to work on his social life.



[Joe's parents had] no idea that Joe could ever be independent and it simply never occurred to them that he would need decision-making skills in order to function as an adult.

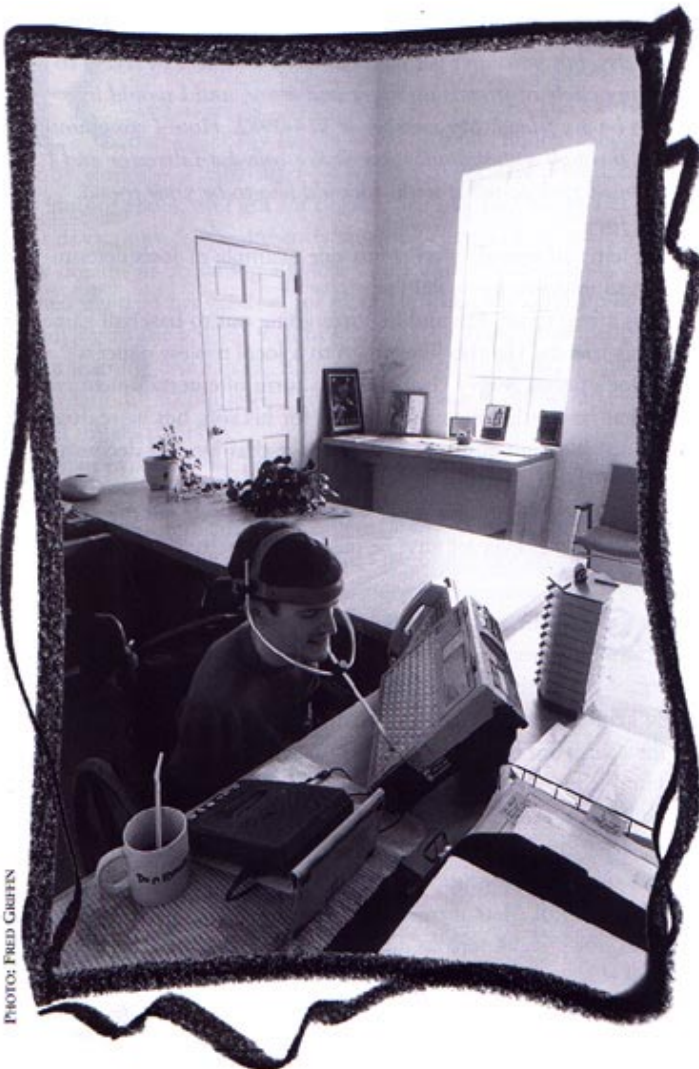


PHOTO: FRED GREEN

Key to Success

Joe's responsibilities are his responsibilities. Assistive technology for communication opened the way for Joe to manage his own apartment, two jobs, and a social life.

Joe knows that having a social life is his responsibility and that he needs to get out and socialize with people, yet he confesses that it's hard for him to take social risks. For example, recently he had gone out to lunch alone when he saw two women come into the restaurant. He noticed that they were looking at him. He wanted to go over and talk to them but he didn't.

In an attempt to make it easier to introduce himself and get to know other people, Joe has written an introduction:

"Hello, my name is Joey Hill and I have a disability called cerebral palsy, but you can't get it, I was born with it. I'm trying to build my circle of friends up more and more, and I would like you to be my friend. My number is 324-0982. How I communicate is through a communication device called a Liberator and I use a head stick to use it with. I would like to be your friend. From, Joey."

This letter of introduction is just one example of Joe's determination to improve his social life.

Joe is a real sports fan and he loves going out to baseball games with his friends. He also likes to go to a local topless dancers' club. Joe's father is very clear that this form of entertainment is not what he would personally choose for his son, but he realizes that since Joe is an adult, he gets to make that kind of decision for himself. It is a part of self-determination.

Joe has this message for other young people, "Reach for the future and never ever let anyone tell you different."

—Tucson, AZ



**Robin Swasey:
If You Need Help, Ask for It**

Robin is 20 years old and she has lived in Tucson most of her life. While Robin has had various job experiences, such as doing clerical tasks at a hospice, she has found that she really enjoys working with children. She currently works as a baby-sitter—a job which she saw posted, called to inquire about, and got for herself. She has also worked at different day camps. She is presently studying education in college and she dreams of becoming a teacher someday. Robin feels successful when she tried her hardest, for example when she stays up late studying so she will do well in school. Like many other people with learning disabilities, Robin is offended by the label “mental retardation.” Robin says, “I’m slow at reading and writing—that’s what my disability is.”



Robin explains that being an adult means that she is older and more mature. It also means that, “You get to do more fun stuff,” whereas teenagers don’t get to do as much of what they want to do. She certainly likes having fun. One of her favorite activities is going to the water park and swimming in the wave pool.

Robin lives in an apartment with her roommate Alice. It took a lot of time and planning for Robin to get her own apartment, which she finally got when she was 18. Her first roommate did not work out so well, though. As Robin’s mother explains, the other woman was apparently not yet ready to live on her own and so she dealt with the stress in unproductive ways. Living with Alice, on the other hand, has worked out extremely well. A local service agency hooked them up as roommates and helped them find their apartment.

For the family, the process of having a young person who has a disability grow up is not always easy. Fortunately, Robin’s family was able to have open communication so



“I’m slow at reading and writing—that’s what my disability is.”

so that when a concern would arise regarding Robin and her needs, they were able to share their feelings and brainstorm solutions to potential problems. Robin’s Personal Futures Planning team was useful in facilitating such discussions. For instance, some family members were concerned about Robin’s safety when she was moving out on her own. After sharing these feelings, they made sure Robin knew how to stay as safe as possible by taking precautions, such as keep her door locked and clearly posting important phone numbers to call for help.

Robin gets approximately 40 hours of agency support per week, down from 60 when she first moved out. She is able to use these hours however she needs them, whether it is at school or at home doing the laundry. She chooses to use most of her support hours for homework, which takes a good deal of her time, and for help developing social opportunities, which Robin sees as the cornerstone of a happy life.

Robin knows from experience that sometimes you need to fight for the important things in life. She was in special education in middle school but she did not like that placement because the work was



not challenging enough for her and her teachers tended to talk down to her. In high school, her mother was told that Robin could either be in special education and receive special services or she could be in regular education and receive no supports or services. She and her family found it necessary to exercise their rights to get an appropriate educational placement and services for Robin. They did finally get a regular education placement with supports, but

even then they felt that the teachers did not expect Robin to benefit from the experience. Although Robin was not getting high academic grades, she was definitely getting a lot out of her classes. They had to work with the teachers for them to adjust the amount of work so that Robin could succeed and graduate from high school.

Robin's mother had worked so hard to obtain appropriate supports and services both in and out of school that, in a way, it has been a relief for her to see Robin grow up and move out on her own. Her mom explains that being an advocate can be a lot of work, but that it is extremely important. Her advice to other parents is that if you want your son or daughter to be independent, you are going to have to force the issue. She goes on to encourage parents, "If you need help, ask for it. If you are entitled to it, demand it."

—**Tucson, AZ**

Key to Success

1. Family concerns about Robin's safety were neither ignored nor treated as insurmountable barriers. Instead, security issues were directly addressed by her Personal Futures Planning team with a set of preventative measures to increase her personal safety.
2. Robin and her mother both fought hard for her to have a high school education that would meet her educational needs, the legal right of all K-12 students with disabilities. As a result, she was able to get the most out of her high school years, and she continues to take classes and study hard.



Gus Estrella:**Accepted as a Person, Not as a Person with a Disability**

Gus is 34 years old. He was born in Nogales, Arizona and then lived in Nogales, Mexico for three years. He and his family moved to Tucson when he was a young child so that Gus could get some of the things he needed, since there were no services in Mexico for children with disabilities and he has cerebral palsy. Gus was in school before passage of the IDEA law that now requires schools to include people with disabilities, yet he was fortunate enough to have good teachers who were willing to help him get ahead. They pushed him and challenged him to do more and to try different things. Gus says that this kind of instruction and encouragement really helped prepare him for his adult life. It gave him courage to try new things.

Like his teachers, Gus' parents never held him back; not did they let people get in the way of his education. For example, when Gus entered junior high, he needed to attend school in a neighboring district. His family made the appropriate arrangements, but the district where he lived refused to pay for needed services. Without any warning, no bus was sent to pick up Gus for school on the first day. So his mother took him to school and then got on the phone with the head district official. Three days later, the bus finally came to take Gus to school. Nine months later, the family chose to move into a different school district to get better services for Gus.

In high school, Gus really wanted to be like the other students. He took the same classes as the others, but without a power wheelchair he did not have the opportunity to make friends and to go out with his peers. In college, things changed. He discovered that having a power wheelchair was essential for getting around and for building friendships. He also lived in the dorms, putting

him in the middle of a great social scene. He went regularly to the basketball and football games with his college buddies.

Gus graduated from the University of Arizona in Tucson with a bachelor's degree in creative writing. He candidly explains that his vocational Rehabilitation counselor "wasn't thrilled" about his choice of major. Gus has a great sense of humor, though. He says that his counselor was afraid that with a creative writing degree, the only job Gus would be able to get would be waiting tables. He jokes that her real fear was that someday he would end up being her waiter and he would find out what a terrible tipper she was!

All joking aside, Gus' creative writing degree prepared him well for speech-writing, an essential part of his job today. Gus has been working for United Cerebral Palsy in Washington, DC as a Policy Fellow for two years. His job is to make people, especially lawmakers, aware of the value of giving the person with a disability the equipment needed in order to remove barriers from daily life. Gus was active in



Gus has been working for United Cerebral Palsy in Washington, DC as a Policy Fellow for two years. His job is to make people, especially lawmakers, aware of the value of giving the person with a disability the equipment needed in order to remove barriers from daily life.



PHOTO: FRED GARDIN

Key to Success

1. A communication device and a power wheelchair gave Gus irreplaceable access to the world in two critical ways: communication and mobility.
2. Gus was pushed and challenged to do and try things as a child, both by his teachers, and by his family, who moved to Tucson to get the services he needed.

meetings with the people who wrote the language of the 1997 IDEA reauthorization. He says that some of those people did not even know what assistive technology was. So, Gus talked to them and showed them, too. He is articulate and skilled in using his augmentative communication device called a “Liberator.” Gus also does a lot of traveling for his job. In one month he traveled to Philadelphia, Baltimore and Pittsburgh to give speeches. According to Gus, doing so much traveling is fun, but it can be challenging because each hotel seems to have a different definition of “accessible.” Nevertheless, the job is exciting and satisfying.

Gus explains that having a job is just one part of being successful. He says that “the rest of success includes a family who will be there no matter what you do, and also to be accepted by society as a person, not as a person with a disability.” With this statement, he acknowledges the impact that society has on a person’s ability to be successful, and gives credit where it is due to his family. Gus wants to let parents know that “they should not hold their child back. If they want to try something, let them and if they fail, they know what not to do next time.” His parents have helped him by letting him live and learn.

Gus’ Liberator is an incredible device because it gives him speech and he uses it very effectively. However, it does have one major drawback: it is only programmed for English. It is limiting for Gus because he cannot speak with people, including some family members, who are Spanish-speaking. Apparently there is a new augmentative communication device which uses Spanish. Gus is hoping that they will come out with one which is bilingual. Perhaps the next era of disability awareness will include more cultural sensitivity.

—Tucson, AZ



**Mike Williams:
Choices**

Mike is almost 16 years old. He is an excellent example of the Personal Futures Planning model in action. His PFP circle of friends includes his parents, a neighbor or two, a friend, his godfather, his middle school resource teacher, and his PFP facilitator.



Mike, who has Williams Syndrome, a neurobehavioral disorder, has been gaining valuable experience in making important life decisions for himself. For example, Mike is currently working at a high school doing some janitorial work. He has also worked at a library re-shelving books and as a teacher's aide. At a special event called Challenge Air, Mike and his family went up in a Cessna and Mike even got to help fly the plane himself. Mike has visited a local Intel plant to see their robotics, and he will soon be going to a local radio station for a tour and to make a radio spot with other youth with disabilities. All these different experiences help Mike to see for himself what he likes and, just as importantly, what he does not like. (For example, Mike is now quite clear that he does not enjoy scraping gum off school desks.)

Mike's mother wants other parents to know that "transition starts from day one," that it is not just a high school term.



Mike's circle of friends has also helped Mike achieve another one of his dreams. He had really wanted to walk home from school by himself, but his mother was concerned about his safety. After identifying this goal, members of the Key club at Mike's school were asked to walk with Mike after school. His student peers helped him for about a month, taking natural opportunities to teach him about safety issues such as crossing at a light. After a month, the students felt that Mike was capable of getting himself home safely on his own. And he was. Mike is now quite proud to share that he walked home by himself for the rest of the school year.

Through the Personal Futures Planning process, Mike and his family have become increasingly aware of choices.

Key to Success

1. Mike's family and Personal Futures Planning team have exposed him to many possibilities for his future. He is quite aware of choices in general, and at sixteen, he already knows a lot about what kinds of work he likes and doesn't like.
2. A group of Mike's age peers were invited to help him learn an important skill—walking home from school by himself. This provided the teens with a meaningful social opportunity, and Mike's mother was able to practice letting go in a small way.

Mike is now given more opportunities to participate in making decisions for himself, including educational decisions. Mike has participated in two IEP meetings at school where the members of his IEP team point out the classes they think Mike would like and have him choose which ones he wants. Mike's new-found appreciation of choices is reflected in his advice to other young people regarding job seeking: "Just look out and around to see what you want...in the newspaper and the phone book." He really enjoys the freedom of choice.

These kinds of changes are important, but not necessarily easy for parents. As Mike's mother says, "I'm sad that he's growing up, but I'm also very happy to see that he's growing up and learning to be independent. I'm positive that he'll be able to take care of himself. He'll grow up and be fine." Seeing all that Mike is capable of doing has been a real relief for her.

Mike's mother wants other parents to know that "transition starts from day one," that it is not just a high school term. She explains that "once parents stop feeling sorry for themselves," they can begin educating themselves on what it is that they do have, what it is that they need, and how to go about getting what they need. She

wishes that they had formed their circle of friends even sooner than they did. She explains that it is very helpful for young people whose judgment is not always the best in deciding who is a friend and who is not. It provides a wealth of trustworthy people who can offer support and help the young person to make informed and well-considered life decisions.

—Phoenix, AZ



**Cynthia Berkheimer:
I Love Life!**

Cynthia is 28 years old, a very assertive woman who is clear about what she does and does not want in life. While Cynthia has autism, a slight speech impairment, and deafness in one ear, she says of herself, “I could do almost everything if I put my mind to it.” Cynthia dreams of being a dancer and performer, a movie actress, a singer and a songwriter. She already plays the guitar. She loves music a lot and she would like to go back to school to study music in college.



One of Cynthia’s dreams is to write a book about her life. She would like to write about what it was like before she started talking, when she was seven years old. She remembers how frustrating it was to not be able to tell people what she needed and wanted. She would also like to write about her family. Cynthia is Irish-American and she knows a lot about her family history. She would like to go to Ireland, and learn more about the Irish people.

Cynthia has been working at a grocery store as a courtesy clerk for about two months. She says, “It keeps me busy—that’s one thing I like about it.” She also likes helping people, which she gets to do when she bags groceries and takes them to customers’ cars. Although she works between 30 and 40 hours a week, Cynthia still finds time for her friends and hobbies, which are important to her.

Cynthia takes initiative to make sure her social needs are met. She has quite a few friends, and she enjoys going out with them to the mall, to the movies, to plays, and to concerts (she likes all kinds of music, especially rock ‘n’ roll). She likes to go out and party and dance. She also likes to help her friends out when they’re having a hard time. “They talk about their problems,” she explains, “and I listen, because we’re friends.” One friend that made a big difference to Cynthia was a babysitter and mentor named Sandy, who



taught Cynthia to read, write, and tie her sneakers. “She was being a good friend at the time,” Cynthia explains.

Now her mother is supportive of her daughter’s sexuality. She explains, “It’s just another facet of who she is. She’s my child, and there is nothing that could ever turn me against her.”

Every month, Cynthia volunteers at the local independent living center, mailing out their newsletter. She likes the newsletter parties because she gets to help out, have pizza, and make new friends. The independent living center sponsors support groups, social events, and classes for people with disabilities, and Cynthia enjoys participating. She has especially enjoyed the outings she has gone on with other people who hang out at the independent living center. For instance, they recently went to the zoo, and one time they went to a baseball game. Since different people go on each outing, each one is an opportunity to make new friends.

Cynthia has not yet had a significant relationship, but she is very clear about her sexuality, that she is gay. She explains that she has always had strong feelings for women. Cynthia is hoping to become more connected with the gay/lesbian community. In fact, she already belongs to a social club for people who are gay and she has visited the local gay community center.

At first, Cynthia’s mother was unsure about her daughter’s



sexual orientation, thinking that Cynthia was being confused. “But we did a lot of talking, her and her sister and her brother and I, and Cynthia was quite clear on the matter.” So now her mother is supportive of her daughter’s sexuality. She explains, “It’s just another facet of who she is. She’s my child, and there is nothing that could ever turn me against her. I can think of a lot worse things.”

Cynthia, her mother, brother, and sister are all very important to each other. She lives at home with her mother, and the two of them really appreciate each other. Since her mother’s health isn’t very good, they help each other out a lot. Her mom gives her rides home from work after dark, and Cynthia helps with household chores and grocery shopping.

Cynthia’s definition of success is to work hard and to do your best, which she feels she is doing. Her advice to other young people? “Enjoy your adulthood. It can go by a lot faster than you’d think...I’m planning on living to at least a hundred. I’m serious! I love life!

—**Tempe, AZ**

Key to Success

Cynthia works hard at finding opportunities to make new friends. She does volunteer work projects, and takes initiative in other ways to have a fulfilling social life.



**Joel Hornstein:
Good Job!**

Joel is 23 years old. He has an agreeable personality and he enjoys pleasing others. He is highly capable and intelligent, scoring high on IQ tests. While Joel has autism, his family has remained firm in emphasizing his strengths.

Many people would see Joel's extreme need for organization and neatness as an obsession, a weakness to be corrected. Instead, Joel, his family and his job coaches have been able to see these qualities as strengths, turning them into very marketable and employable characteristics. Now Joel works full-time at a library, sorting and re-shelving books and other materials. His mother explains that, "When you're looking at adulthood, you just have to look at what works despite the disability, and then how to use it creatively."

Joel received good support in getting the experience needed for his current job. His high school staff was able to find him volunteer work in a library, and his mother was able to provide other supports to make it work. After volunteering for five years, though, Joel needed to move on to a paid position.

When Joel went on the interview for his current job, he went with two job coaches, one of whom interpreted in sign language for Joel (since visual signs are often easier for him to process than verbal words). Even though the job coaches worked hard to convince the interviewers that he could do the job, they were reluctant to hire Joel, who quietly rocked in his chair and ignored the interviewers. Finally, one of the job coaches asked if the library had a test for prospective entry-level employees. They gave Joel a 50-question test on alphabetizing and numerical ordering skills which he absolutely zipped through. As Joel was about to hand it back to the inter-

interviewer, he whisked it back, immediately erased and changed three answers, then handed it over and resumed looking to the side away from them. The interviewers checked the key and found that it was 100% current and it took Joel one tenth of the time it would take anyone else! So they decided to consider Joel for the job, and while it took about six weeks, Joel finally got hired.

Joel learned his job responsibilities with remarkable speed and accuracy. His job coaches worked with him for a little while, but they also worked to empower the library staff to communicate with him directly, so that Joel would be better able to work with them. Then they faded away as soon as possible. Joel now works full-time on his own without the support of a job coach.

Joel still benefits from the behavioral training he received when he was younger. For example, he reinforces his own positive behaviors. When he finished a job and there is no one else to compliment him, he'll give himself a big thumbs-up and tell himself, "Good job!" He'll even do the same for his co-workers, telling



them when they have done a good job, too. Joel really likes his work and he has made quite a few friends there who, according to Joel, are all "very nice."

The other employees at the library—Joel's natural supports—have learned to be creative in working with Joel to help him have a



When he finished a job and there is no one else to compliment him, he'll give himself a big thumbs-up and tell himself, "Good job!"

Key to Success

1. Joel's supporters found a way for him to demonstrate his skills in a job interview, convincing interviewers that he was indeed well qualified to perform the job.

2. Joel's family and job coaches have worked to develop many natural supports in his life—people who know what works for him and lend a hand on the job or at synagogue without being asked each time or getting paid for it. They can see that there's something in it for them.

successful work experience. For example, since down time is hard for him, they made a box and labeled it "Joel's Work." It contains clerical filing tasks for him to complete when there are no books to sort and shelve.

Joel's mom feels it is important to utilize natural supports in many areas of one's life, not just in employment. She acknowledges and truly appreciates Joel's friends and supports, especially the people in her family's own Jewish congregation. Joel enjoys the predictability of going to services each weekend, of reading from the same book, of sitting among the same familiar people every week and celebrating the same holidays each year. This repetition provides a form of structure and safety for Joel, which is very important to many people who have autism.

In his spare time, Joel likes to watch movies, listen to music, and go to the mall. He also likes to hike and to travel and he loves riding roller coasters. In fact, Joel is going on a trip to southern California soon. He described the itinerary as including the San Diego Zoo, Magic Mountain and Disneyland, as well as some really great places to eat!

Joel's special hobby is collecting postcards. He just loves getting them and reading the messages people write. He has an incredible collection now, with postcards from around the world. If you would like to send Joel a postcard, you may do so and address it to:

Mr. Joel Hornstein
5623 E. Grandview Rd.
Scottsdale, AZ 85254
—**Scottsdale, AZ**



**Lisa McCaslin:
Fun-Loving and Responsible**

Lisa is 35 years old. She is a responsible woman who values herself and who likes to have a good time. For Lisa, having a developmental disability simply means that she does things a little slower than other people.



Lisa has learned some valuable lessons from her past job experiences. She worked in a sheltered workshop for quite a long time when she was younger. Even though it was boring and she wasn't learning new skills, it was hard for her to leave. After that, she worked at two fast food restaurants. She says that working at those places was okay at the beginning, but she decided it wasn't for her because her bosses were "mean and cruel" to her. A good relationship with her boss is important to Lisa and she knows that she deserves to be treated well. So she decided for herself that she needed to get out of the fast food business, and with the help of her mother and a friend, Lisa put together a resume and set out to find a new job.

Lisa has been working at a local restaurant, the Prescott Pantry, for 5 years now, bussing tables, doing dishes, serving soft drinks and collecting tips (which are split at the end of the day). While working, Lisa may strike up a little conversation with the customers. The job works out really well for her. She enjoys all the praise and thanks she gets from her boss. She also enjoys the good paycheck, the raises, and the bonuses, too.

Aside from being a working woman, Lisa also likes to have fun. She goes to the movies sometimes and she likes to go out dancing. She likes to go out and have a drink once in a while, too. One good thing about being older, Lisa says, is that "I don't get carded anymore—I used to!" She's been to Laughlin, Nevada, where she tried a little bit of gambling and she had done an extensive amount of traveling with her mother.



Being responsible is a very important element of adulthood. For Lisa, that includes being a registered voter. She voted in the last presidential election.

Lisa's best friend is her boyfriend. They have been together for two years and they enjoy going out when they have time. Lisa shares that they like to hug and kiss, though they have chosen not to be sexually active. In her early 20s, Lisa made a personal decision not to have children. She decided that she does not have the patience and the time for children, and that she does not want that kind of responsibility. Part of being responsible is knowing yourself and your own needs.

Being responsible is a very important element of adulthood. For Lisa, that includes being a registered voter. She voted in the last presidential election. Lisa has learned to take responsibility for making phone calls to take care of things for herself and she has also learned how to ask for assistance when she needs it.



PHOTO: FRED GRIFIN

Self advocacy is another part of being responsible as an adult. Lisa is the president of the local self-advocacy group. She received the 1996 Outstanding Self-Advocacy Award from the ARC as well as ARC's Citizen of the Year Award in 1995. Her advice to youth with disabilities is, "Keep on trying. Don't give up, I know its hard out there. Just keep on working on it."

Lisa's mother remembers receiving what felt like a "sentence" from a doctor who said that Lisa would never develop beyond a certain point; she wishes she could show that doctor all that Lisa has accomplished. Fortunately, she also remembers a teacher who pounded her fist on the table saying, "You must demand that she accomplish, you must insist that she do the best that she can."

Presently, an important goal for Lisa and her mother is to grow away from each other more. Lisa lives at home with her mother but she has not yet spent the night at home alone. Lisa is comfortable with the idea, knowing that she can take care of things for herself, including cooking and doing laundry. However, it is not such an easy thing for Lisa's mother. Lisa's mom prides herself in knowing that she raised Lisa as she would any other child, expecting her to achieve her goals and advocate for herself. In this area, though, she says that she has never really had to let go, and she is finding it difficult. So they plan on taking steps toward their goal, perhaps having her mom stay with a friend in town for the night, before leaving Lisa at home by herself for longer periods of time. Lisa and her mom will work together and grow together toward the goal of Lisa living out on her own. Considering Lisa's abilities and sense of personal responsibility, it seems well within reach.

—Prescott, AZ

Key to Success

Lisa has been supported in making her own informed personal decisions about everything from work choices to dating, sexuality, and having children.



**Cody Brockmier:
Have Fun!**

Cody is 18 years old and he is in his last year of high school. While Cody does receive some special education services, he does not think of himself as having a disability. He loves football and he spends a lot of time playing center position on his high school football team. Last year he and his team even made it to the state competition in Phoenix. During his free time, Cody likes to hang out with friends and go to the movies, eat out, and go bowling. Cody also enjoys playing around with his little cousin Brock, who is three.

Cody lives with his adoptive grandparents. On the weekends, he works at Eastern Arizona College, where his grandparents run the cafeteria and food services. Cody used to work as a cook and now he washes dishes. He'd like to be a cook again, but his football schedule does not allow for it. Last year Cody worked as a dishwasher at a summer camp. He found the job himself—he decided he wanted it, called up the boss, and got the job. Cody explains that it took some courage, and that he was able to get some help doing it. Now he knows that he will always be able to get a job in food service since he has so much experience as a cook and a dishwasher. Cody's family knows it is important for him to work somewhere other than with his adoptive grandparents. While he has learned many important work skills and values from working with them, he needs to move on to other work settings. Cody is still exploring his options before deciding what kind of work to settle upon.

Cody's family has been instrumental in helping him to formulate and work toward achieving his life's goals. For example, Cody says, "They make me go to school and make me stay out of trouble." They also helped him to save him money in the bank to buy a bicycle. He uses that bicycle a lot! It gives him independence and free-

dom that he didn't have before, which he says is really good. Cody also has a driver's license now. He had gotten in some trouble a while ago while driving, and he had to work hard to pay off that ticket before he could get a license. Cody feels really good that he took care of that situation and was able to move on. Being responsible in this way has helped him to feel successful. For Cody, success also means finishing school. He has been working hard at school so that he can graduate.



He found the job himself—he decided he wanted it, called up the boss, and got the job.

Cody and his parents are Apache. While he has lived with his mother from time to time, he has been raised primarily by his white adoptive grandparents. Through Personal Futures Planning, Cody uncovered a deep desire to learn about his Apache culture. Cody and his PFP team found creative ways for him to learn about his people, such as taking a class on Native American culture at EAC. He also visited his grandfather on the reservation, and spent time with his mother, sister, and little brother. Through these experiences, Cody has learned a lot about his heritage, culture, and religion. He now has a realistic rather than a romanticized view of the culture so that he can make educated choices about



how much he wants it to be a part of his life and to what extent he will participate in it. Taking this step also increased his motivation for taking charge of his work, transportation, and education. Cody's maturing into young adulthood has been a challenge for his adoptive grandparents. As he has gotten older, he has been making

1. Cody's adoptive grandparents have created step-by-step opportunities for Cody to take responsibility for his financial life, from job opportunities to saving for a bicycle to balancing a check book.

2. When Cody identified his interest in his heritage and explored it for himself, he became clearer about his goals in other parts of his life.

more and more decisions on his own. Watching Cody make decisions which could potentially hurt him in some way has been a particularly difficult, but necessary, part of letting him grow up. Through these life experiences, Cody has learned important lessons which he would not have learned otherwise. His grandparents have been diligent in giving him increasingly more responsibilities. For instance, they are currently taking an intermediate step towards getting Cody his own bank account. They keep his money in their account with a separate ledger of deposits and withdrawals, giving him his money whenever he asks for it, so he can learn to manage his finances on his own.

Aside from all the seriousness of becoming a young adult, like finishing school, working, and saving up money, Cody has some advice for other young people: "Have fun!" After all, that's what helps him.

—**Thatcher, AZ**



**Bill Sloan:
Believe in Yourself**

Bill is 36 years old. While he was a student at the University of Arizona and playing on their hockey team, the Ice Cats, he sustained both a spinal cord injury and a traumatic brain injury in a motorcycle accident. Fortunately, Bill's family—mom, dad and four siblings—is, as his mother describes it, “tight.” After the accident, they searched for a comprehensive and progressive rehabilitation program which they found in Colorado. The family accompanied Bill to Colorado and encouraged him to stay strong and continue with his dreams.

Twelve years later, Bill's interests still include hockey (he is a regular at the Ice Cats games) and going out with friends to the comedy club. Bill is a pretty busy guy. He works at an assistive technology center doing database management two days a week. He also helps his parents do computer work for their business one day a week, and he goes to school two days a week. He is currently studying computer science at a community college to see if that might be a career he would like to pursue.

Bill has received awards for Volunteer of the Year and has had an article written in the paper about himself and his partner O'Malley, and eight year old golden retriever service dog. O'Malley helps Bill in such daily tasks as picking up things he may have dropped, bringing him his breakfast, and taking his socks to him. She never leaves his side. In fact, O'Malley added a lot of independence to Bill's life, so that he could do what he wanted. It was then that Bill decided that he could drive, he could work, and he could go to school. O'Malley gave Bill hope again. She is a very cherished and appreciated part of the Sloan family and she even gets a special stuffed dog for Christmas each year.

Bill's independence is also shown in the fact that he drives his own van. His parents collaborated with the Lion's



Editor's Note:
Although Bill does not technically have a developmental disability, his story adds useful information to this handbook.



when Bill registered with Vocational Rehabilitation, he was denied services because his counselor said he was “unemployable.”

Club (Bill did a lot of volunteer work for them before his accident) to add a lift, power door, and power seat to the van. Its great for Bill to be able get himself where he wants to go without relying on others.

Bill and his parents have trusted in his abilities ever since he came out of his coma after the accident. At first, he used an alphabet board to spell out the answers to questions. While doctors were pessimistic about Bill’s future, it was clear to bill’s family that he still have good cognitive functioning and long-term memory. Short-term memory is still a bit of a challenge for Bill. But he is willing to do what it takes, for example, reading over something a few times to let it sink in. Now, bill has two augmentative communication devices to talk to people (instead of just an alphabet board). He is able to type well, so he just types in what he wants to say, and the machine will either display the text or say it out loud for him.

Through dedication on Bill’s part and with a lot of help and support from his family, Bill has come a long way in recovering from the accident and adjusting to the many changes in his life. But when Bill registered with Vocational Rehabilitation, he was denied services because his counselor said he was “unemployable.” This rejection was very frustrating for Bill and his family, but they did not give up. As Bill tells other young people, “don’t believe everything a person says. Believe in yourself.” In keeping with this philosophy, Bill and his family requested another VR counselor, and then another one, until they finally found one who also believed in Bill. Vocational Rehabilitation

has since been proven wrong in its initial assessment. Bill has shown himself to be a very successful and employable adult. He’s not one to give up. He keeps on going.

—Tucson, AZ

Key to Success

In the face of pessimism and discouraging advice by experts, Bill and his family kept believing in him and pursuing his goals.



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**Cyndy Tyler:
Everyone is Disabled to Some Degree**

My name is Cyndy. As a child I was diagnosed with serious learning disabilities and coordination problems. I grew up in the Phoenix area. As a child I was not able to keep up with the other children in school. There was not a resource class for me to attend in those days so that I could get some help with my school work. At the end of third grade the principal wanted to keep me back a grade. I am grateful that my parents knew their rights and stood up for me. They insisted I be given an intelligence test. The test results showed that keeping me back a grade would not help me very much. Instead I was sent to Devereux, which was the only special education school in this area that helped children who had serious emotional or learning problems. This was done mostly at the school district's expense. All this happened in 1968 which was quite a while before PL 91-142 (IDEA) was passed.

I liked this school because we did fun activities as well as work. For the first time I felt successful and I thought I fit in with the other children. The teachers worked with me a lot and I was able to catch up with my peers in the elementary school.

Because I progressed so fast, halfway through fifth grade I was transitioned back into a regular elementary school class. However, soon I started to fall behind in some of my classes (math, science, and physical education) again. Even though I was having difficulties I was passed from grade to grade. I think my teachers knew I was trying and didn't have the time to give the individual attention that I needed.

By the time I reached high school there was a resource class that I could attend. I was in this resource class for two and a half years. I was taken out of it because my teachers did not think I was benefiting from it. This was



Editors Note:
*Cyndy surprised
us by faxing in
this story.
Thanks Cyndy!*



***my resource
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gree.
Since graduating
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Bachelor's level
of knowledge.***

fine with me. I had always been a self-starter who was better at teaching myself things anyway.

I will always remember it made me feel really good when a biology teacher told me she thought I was smart even though some of my grades were poor.

I will also remember that my resource teachers laughed at me when I told them I wanted to go to ASU and get a Bachelor's degree. One of them told me I should just worry about graduating from high school and then maybe I could go to a vocational school.

I did not believe them and went to ASU and got a Bachelor's degree. Since graduating twelve years ago I have always done work that required a least a Bachelor's level of knowledge.



Currently I work as a Family Support Specialist at Westside Social Services. I have worked with people who have had various types of disabilities over the years. I feel that often people look at a person's disability first and everything else about them becomes secondary in their minds. I feel that to help a person with a disability succeed, his/her family, teachers, and therapists should have confidence in him/her and look at their strengths, interests, and feelings before their disability.

Even though I continue to have some problems that are associated with my learning disabilities, I feel successful. Success to me means having friends that I can talk to and fit in with. It also means making my own choices and feeling good when I accomplish goals that I have set for myself. It means finding a career and hobbies that I enjoy and I am good at.

Over the years I have come to realize that everyone is disabled to some degree. I have also come to accept that my disabilities are a part of who I am.

Some of my future goals include getting married, having a child, getting a graduate degree in counseling or social work, and becoming a foster parent.

—**Phoenix, AZ**

Key to Success

Cyndy's ability to see her own strengths, interests, and feelings first, before her disability, gave her the confidence to overcome other people's low expectations of her.





Insights About Transition to Adulthood

This is a summary of important ideas about transition to adulthood gathered from our project. Unfortunately, it doesn't really cover everything a family needs to know, but we hope that it will help put things in perspective. We've organized it into three major sections:

EMPOWERING FAMILIES

Families need open, honest discussion, and timely information presented in non-threatening ways.

DEVELOPING SUPPORT

Real choices, changing relationships, and access to resources are the building blocks of a supported adult life.

BUILDING COLLABORATION

Community networking is pivotal and catalytic, especially when it involves adult role models.

E M P O W E R I N G F A M I L I E S

1. Families, including youth with developmental disabilities, need a daunting amount of information about transition.

★ Visions of what is possible are limited to what is known and familiar. Information is power, whether it comes from a role model, a book, a teacher, etc.

★ Families have varying levels of comfort with getting, asking for, having, or not having information. In addition, families have limited and inconsistent access to needed information about:

- Special education options and methods, such as community-based instruction, appropriate placement, etc.,
- IDEA, transition planning, and IEPs,

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- Civil rights, the independent living movement, and disability culture,
- Adult service systems, especially vocational Rehabilitation,
- Supported employment,
- Assistive technology for communication and mobility,
- Housing and supported living options, and
- Techniques and creative avenues for handling bureaucratic obstacles.



Information is especially lacking in rural communities and in Spanish and other languages.



In general, families from Hispanic, Native American, and other non-dominant cultures feel less informed and less confident about securing supports outside the family.

2. Families need to receive information in a personalized way, at the pace, complexity, and timing that matches their lives.



While each family has different needs about time of day, format, and pace of learning, many people learn best through examples and role models. Everyone needs to be able to relate new information to information they already understand or have experience with.



Families of youth with developmental disabilities tend to have very full lives, making it hard to find time to plan ahead. A major family event such as a wedding, illness, surgery, etc. can mean that a family will have no time or energy available for transition planning for months at a time.



Crisis points in the transition process are opportunity times when information is sought and best assimilated. Faced with an important decision, every family will want to make the best choice possible.



In retrospect, families almost always wish they have started transition planning earlier, even if they literally had no time or resources to do so.



Fears are based on real needs for physical and emotional safety that should be met with information, planning, skill development, mentoring, etc.

3. Parents and other family members need to express their concerns and fears, and have them addressed somehow in the transition planning process.



Fears that are discounted or unrecognized can become exaggerated.

4. “Support” is seen differently in different cultures. Families that live in more than one culture can feel torn by these differences.



For example, in some Native American tribes, a disability is caused by a taboo broken by the parent during pregnancy.



Many Hispanic/Chicago people strongly value support provided within the family, and feel that looking for support outside the family is difficult.



Sometimes a family chooses to release or partially release deeply-held cultural traditions or beliefs to pursue more supports.



Some families prefer to maintain the values of their extended family and community even if it means accepting a more limited level of accessibility for the family member with a disability.



It can be very difficult when a family feels caught between two cultures. In such situations, there are no right or wrong choices. Families need to be supported to make their own choices.

5. In every culture, parents of children with disabilities tend to feel guilty about the disability.



Guilt can be like cement making it harder to let go. However, raising children, particularly children with disabilities, is hard, time-consuming work. Every parent deserves to look back at the successes of that good, hard work, and be pleased. If a parent could possibly have done a better job, he or she certainly would have.

DEVELOPING SUPPORT

1. “Support” refers to a whole range of encouragement, equipment, activities, and systems designed to accommodate a person’s weakness or disability so that their abilities can flourish as they participate in every aspect of life.



Everyone needs support in their lifetime. Two examples are that everyone needs help at times with transportation, and many offices have a person whose job is to provide computer support for people who are computer-challenged.



Asking for help seems to be terribly difficult for most of us. It can even be culturally inappropriate to ask others for assistance.



If parents aren’t comfortable asking for help, their sons and daughter aren’t likely to be either.



Although many people in the community do want to help, offering support can also be quite difficult for people, especially when the help is not perceived as welcome or wanted.

2. Youth with developmental disabilities need to be asked directly and repeatedly for their opinions and preferences, and see real decisions incorporating their view.



However limited a person’s communication may be, every person finds ways to communicate their likes and dislikes, joys and upsets, anger and caring. Everyone can communicate enough to have real control over decisions that affect their life.



There are countless examples of people with developmental disabilities whose abilities have soared beyond expectations when someone persistently and thoughtfully raised those expectations. We can never fully know what a person is capable of, and we certainly won’t find out without acting like more is possible.

- ★ All of us spend years making mistakes and learning to make decisions on our way to adulthood. Teenagers with developmental disabilities have typically had many fewer such chances than their non-disabled peers. Encouraging a person through a learning process of making decisions and mistakes will over time lead to better decision-making.
 - ★ Without those thousands of decision-making experiences, youth with developmental disabilities are likely to lack confidence, mistrust their own judgment, and expect their opinions to be disregarded.
 - ★ Any person newly-empowered to make decisions will test to see if their choices will truly be respected.
-

3. The work of providing daily living supports is a part of parenting that can be passed on to others to support the youth in becoming a self-directed adult.

- ★ This process is uncomfortable. It involves building a set of trusting relationships, and taking real risks. Hired assistants can be unreliable. A person with a disability may not be clear about the difference between a friend and paid support staff. Close friends or family members will make different decisions than a parent might, and they can even turn out to be untrustworthy. But these relationships can also work out beautifully.
- ★ Long range planning is essential, since parents are unlikely to be in their child's life to the end. Some parents think of transition planning as a way of planning for "retirement" from a part of the job of parenting. These parents will always care about and be involved in the lives of their adult children, but they can "retire" from the daily job of providing primary supports.
- ★ Rather than feeling abandoned, most adults with disabilities who no longer rely on their parents for basic care feel respected by this step and strongly recommend it. They want to have adult relationships with their parents that are not possible if they depend on them for daily living supports. This seems to be true regardless of the disability, as long as the support and companionship available really do meet the person's needs.



Starting early with this key process allows more time both for building good relationships and for building a person's judgment about trusting others and getting help appropriately.



Letting go can be painful. In practice, most letting go happens in the face of immediate consequences. Keeping that in mind, it is easy to see that ANY advance planning deserves a pat on the back. Parents need to be forgiving of themselves. Knowing the next step does not always mean a person is ready to take it.

4. Youth with developmental disabilities need full access to communication and mobility, including community transportation.



Several of the stories in this handbook clearly demonstrate the tremendous difference it makes for a person to have access to communication and mobility. Without these two critical resources, many youth with developmental disabilities in Arizona will spend years of their adult lives watching television or attending day programs when they could be working in the community, living in their own homes, and building their own families if they had access to communication and mobility.



Lack of access to communication or mobility is almost always a problem of empowerment. There are bureaucratic hurdles, to be sure, but assistive technology exists to accommodate virtually every disability, and legislative mandates exist for funding. If a family identifies this need early, a precedent can be established in elementary school, when the family can more easily exercise their rights. Families are likely to encounter real obstacles, but by refusing to be intimidated by culture, language, distance, pessimistic administrators, and other factors, then anyone could have access to mobility and communication.



Accessible public transportation is attainable using the same skills and strategies as other assistive technology, with one exception: a community must organize and advocate together for collective transportation needs to be met.

5. Persistence pays off in developing supports for employment and independent living. Many good resources are available, even if it's not always easy to find out about them.



Two of the largest and most important resources are the special education system and Vocational Rehabilitation, both of which are complex enough that families can easily feel intimidated trying to learn about them. Nonetheless, there are sources of clear information, including other people who have learned to work these systems.

B U I L D I N G C O L L A B O R A T I O N

1. Families and communities both stand to gain enormously from increased dialogue between families, agencies, schools, business leaders, and other community partners.



If families and professionals knew about all the existing resources, many more things would see possible.



Programs and service agencies generally don't realize how much they would benefit from welcoming people with disabilities and their family members as essential team members on their staff and on decision-making boards.



Parents rarely feel appreciated for their hard work, knowledge, and caring; instead they often feel criticized as “troublemakers” or “unconcerned.”



Youth and adults with disabilities are not seen as capable experts and potential experts in a highly specialized field which needs to be responsive to them. They are misinterpreted, misinformed, and talked down to in meetings and planning groups because of differences in communication or decision-making style, and because of stereotypes.



In spite of these barriers, one person can substantially improve collaboration for a person's transition planning or community when they decide to do so. Community partners often need and appreciate more information about each other, and they generally want to provide the best service they can.



People wishing to support families need to be trustworthy and persistent.

2. Visible, credible role models are treasures for families in transition and their communities.



Parents benefit greatly from hearing the transition stories of adults with disabilities. A real person's story can ease a parent's fears/concerns about independence, transforming the looming unknown into specific problems to be solved. A role model can put a disability in perspective in the greater human process of growing up, helping parents to understand their son or daughter's concerns.



Youth benefit greatly from hearing the transition stories of adults with disabilities. A credible role model may do as much to awaken a sense of self-determination as any curriculum.



Parents who hear transition stories from other parents can relax some of their fears and focus more on effective planning.



Role models need to be realistic and accessible. They need to come in all genders, colors, locations, cultures, languages, vocations, will all disabilities. They need to be in person, on TV, on videos, in books, in the newspaper, in Braille, on tape, etc. Ideally, every Arizona youth with developmental disabilities would have at least one ongoing personal relationship with a believable role model who has a similar disability and whose life demonstrates something about what is possible for them.



Public Policy Recommendations

EMERGING FROM THE FIRST JOBS ARIZONA NATIONAL DEMONSTRATION GRANT

As a society, we face the need for new public policy in relation to those among us with developmental disabilities. The stories in this handbook provide glimpses of the untapped potential that can be realized with the support and encouragement of family and friends. Public policy needs to support these natural networks to make it possible for people with developmental disabilities to be recognized as contributing members of the workforce.

After a brief historical overview, we will address two key policy issues facing decision-makers, and provide specific recommendations for each issue. The two key issues are capacity-based vocational assessment of the individuals, and building employer capacity to support workers with developmental disabilities. We will then explore a possible catalyst to create this change in public policy.

HISTORICAL CONTEXT

Public policies related to services and programs for people with disabilities reflect prevailing social attitudes. We have seen three eras of policies and social attitudes begin and end since the founding of our country, and we are now beginning a fourth era. We will label these eras Pity, Caretaking, Fixing, and Recognizing Capacity.

Before institutions became common, US society at large had an attitude of pity toward people with disabilities. It was an era of private charity, without government services. Then, in the early 1900's, federal and state governments began to establish institutions and training schools. This reflected a significant improvement in public attitudes about disability, from pity to caretaking, corresponding to the general increasing wealth of the country. Half a century later, as scientific and medical successes accumulated, US

society developed a we-can-do-anything attitude. Public policies developed during this period were based on the medical/developmental model of disability, and the assumption that a disability was a problem to be fixed by specialists through training and education.

During the 1990s, this model of disability has been altered by the independent living model. In this model, people with disabilities are seen first as people, with strengths and weaknesses like every other group of people. The corresponding new era of public policy is based on recognizing capacities in people, complementing the growth and development of individuals by adapting environments to acknowledge and draw upon people's strengths.

In this spirit, our policy recommendations aim to increase our society's ability to recognize and support the capacity of people with developmental disabilities as integral, contributing members of society, and the capacity of their communities to meaningfully include them.

KEY ISSUE:

Capacity-Based Vocational Assessment of the Individual

First and foremost, public policy must recognize that people with developmental disabilities have assets that can complement their communities, and this must be done without disregarding real limitations.

Unfortunately, traditional educational and vocational assessments have tended to focus on the skills and abilities a person is lacking, thereby indicating why they cannot be employed in a meaningful way. The typical student has had his/her lack of potential documented repeatedly by the time he/she leaves high school. Rather than identifying how a person needs to be "fixed," assessments should indicate how existing skills can be built upon in practical terms that relate directly to employment situations.

Tied closely to a person's success or fulfillment in employment is personal interest. One's capacity to succeed is strengthened if one genuinely enjoys performing the work, whatever it is.

Public dollars that pay for vocational assessments should:

- Focus on the abilities that a person has, valuing their potential contributions to an employer.
- Be realistic and acknowledge, not disregard, limitations in particular skill areas.
- Identify and draw out a person's interests that might pertain to an employment setting.
- Provide information for developing employment options that match the person's interests, abilities, and contributions to potential employers. This should include ideas for matching and marketing these assets to potential employers, including potential employers identified by the person's network of family and friends.

Person-centered planning, in any of its many forms (Personal Futures Planning, MAPS, etc.) is an example of capacity-based assessment that accomplishes these goals.

SPECIFIC RECOMMENDATIONS:

1. Parents, schools, and Vocational Rehabilitation programs should ensure that vocational assessments purchased are capacity-based (as described above) rather than deficit-oriented.
2. Parents and schools should ensure that vocation assessments conducted during school years have practical relevance to post-school employment settings.
3. Parents should hold schools to the legal requirements of the IDEA, including the functional vocational assessment requirements, starting at age 14.

KEY ISSUE:

Building Employer Capacity to Support Workers with Developmental Disabilities

Public policy should build on the strengths of real community employer networks, and it should direct the resources of the

society toward further strengthening them. Public policy can play a pivotal role in making employment available to many more people with developmental disabilities by empowering employers both to build on existing supports and to provide additional needed supports and adaptations or accommodations for employment.

Successful workers with developmental disabilities rely on extra support that they receive from trusted friends, family, and community members. These “natural supports” are people who spontaneously value a person with a disability as an integral part of their family, neighborhood, workplace, etc. Employers can often rely directly on these natural supports for information about how best to communicate with or train a particular individual, or for other help. Public programs such as Vocational Rehabilitation need to develop and offer expertise in facilitating this process.

Supports needed for employment might also include adaptations or modifications to the work environment (i.e., assistive technology, extra staff supervision, job coaching). In general, these supports go beyond the “reasonable accommodation” requirements of the Americans with Disabilities Act. These services are currently limited, largely due to public policy, which continues to support dependency programs (such as SSI and SSDI), rather than supporting employers to provide accommodations.

SPECIFIC RECOMMENDATIONS:

1. Increase employer capacity to hire people with developmental disabilities by making opportunities available to employers, such as:
 - Programs which strengthen the role of natural supports in developing and/or implementing workplace accommodations for workers with developmental disabilities.
 - Funding for higher accommodation costs in the work environment (i.e., adaptive equipment, supervision, job coaching, etc.). this could be accomplished through a variety of mechanisms, including:

- a) Employer tax incentives.
 - b) State taxpayer dollars for Employment Support Services (ESS).
 - c) Federal taxpayer dollars for ESS.
2. Encourage development of businesses that invest in the assets of people with developmental disabilities by providing incentives (such as start-up costs) for entrepreneurship by people with developmental disabilities and/or their families.

A POTENTIAL CATALYST FOR THIS CHANGE IN PUBLIC POLICY:

The independent Living Movement Welcoming People with Developmental Disabilities and Collaborating with Parent Organizations

The independent living movement and philosophy began in the 1970s as individuals with severe physical disabilities joined together to gain access to higher education, employment, and other aspects of community life. This movement and philosophy grew out of the civil rights movement, Ralph Nader's consumer movement, the emergence of self-help organizations, the de-medicalization of disability, and the de-institutionalization of people with mental illnesses and cognitive disabilities.

In 1979, Congress passed the Rehabilitation Act, which (among many other things) established federally-funded Centers for Independent Living (CILs). CILs are mandated to promote the independent living philosophy by providing four core services: 1) information and referral, 2) peer counseling, 3) independent living skills training, and 4) advocacy, both for individuals and for systems change. Arizona's CILs have strong track records in all these areas.

Although the CILs were created to serve all people with disabilities, they have traditionally focused on individuals with physical disabilities. Because of limited resources and separate funding streams, CILs and people with developmental disabilities have not generally been well informed about each other. Similarly,

CILs and parent organizations have generally not taken advantage of opportunities to work together for common goals. Now, as youth with developmental disabilities who have benefited from inclusive education under IDEA are beginning to leave high school, the challenge of supporting their transitions to adulthood logically calls together these previously separated groups.

Parents have always been the leaders of the developmental disabilities movement. Parents of the emerging generation of young adults have had experiences in which their children have been truly valued by their families, neighbors, and communities. Their children have been included in neighborhood schools and they have developed real, meaningful friendships. These parents, along with their children, now expect more of their communities. These parents also expect more from their adult children. They expect them to contribute and be responsible citizens.

Parents of youth with developmental disabilities will fight hard for their sons and daughters to be recognized for their abilities. At the same time, these parents are anxious to retire from their constant role of parenting. They cognize that they must “let go,” allowing more risk than they are often prepared to assume. They recognize that they want and need others to help in this process, but they don’t know how to ask for help. The help offered must be help that they can trust.

The independent living philosophy and culture, with their emphasis on peer mentoring and self-determination, rightly belong to all people with disabilities. CILs need the fresh contributions of young adults, and they need to work with parents and people with developmental disabilities to accomplish their advocacy goals. Youth with developmental disabilities are in dire need of credible role models. Adult members of the independent living movement can share the lessons they’ve learned as they’ve found their way to integrated community lives, keeping youth and parents from having to re-invent the wheel. Public policies should support

these essential alliances.

SPECIFIC RECOMMENDATIONS:

1. Centers for Independent Living should reach out and welcome people with developmental disabilities and their families fully into the independent living movement, and vice versa. CILs have learned much about accommodations for people with disabilities in the workplace; now they need to learn about the additional accommodations that may be needed by workers with developmental disabilities.
2. Parent Training and Information Centers (and other parent programs) need to collaborate with CILs to improve transition planning efforts. These programs can be natural allies in a movement to create more real employment and living opportunities for youth with developmental disabilities. And they each have much to gain by joining advocacy efforts to change public policy.



Where to Get More Information

Since 1979, Pilot Parent Partnerships has supported families through Arizona on the challenging journey of parenting children with special health care needs or various disabilities. For example, we help parents to acquire skills to become advocates for and with their children, we encourage experienced families to volunteer to help other families, and we assist families, professionals, and communities in becoming collaborative partners. We offer workshops, peer mentoring, and an extensive lending and resource library, including videos, books, and handouts on hundreds of topics.

In recent years, we have greatly expanded our resources related to transition to adulthood. If we were to list all the materials we have available, it would quickly become outdated, and it might seem overwhelming. Instead, we encourage parents and other family members to contact us with questions. We can send information, tell you about other programs, and help untangle confusion about service systems. In many cases, we can pair you up with a parent who has “been there.”

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